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**Information for Behavioral Health Providers in Primary Care**

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## **Lupus Information Sheet**

### **What is Lupus?**

Lupus is a chronic, autoimmune disease that can damage any part of the body (skin, joints, and/or organs inside the body). Chronic means that the signs and symptoms tend to last longer than six weeks and often for many years. In lupus, something goes wrong with the immune system, which is the part of the body that fights off viruses, bacteria, and germs ("foreign invaders," like the flu). Normally our immune system produces proteins called antibodies that protect the body from these invaders. Autoimmune means the immune system cannot tell the difference between these foreign invaders and the body's healthy tissues ("auto" means "self") and creates autoantibodies that attack and destroy healthy tissue. These autoantibodies cause inflammation, pain, and damage in various parts of the body.

- Lupus is also a disease of flares (the symptoms worsen and the patient feels ill) and remissions (the symptoms improve and the patient feels better). Lupus can range from mild to life-threatening and should always be treated by a doctor. With good medical care, most people with lupus can lead a full life.
- Lupus is not contagious, not even through sexual contact. You cannot "catch" lupus from someone or "give" lupus to someone.
- Lupus is not like or related to cancer. Cancer is a condition of malignant, abnormal tissues that grow rapidly and spread into surrounding tissues. Lupus is an autoimmune disease, as described above.
- Lupus is not like or related to HIV (Human Immune Deficiency Virus) or AIDS (Acquired Immune Deficiency Syndrome). In HIV or AIDS the immune system is underactive; in lupus, the immune system is overactive.
- It is estimated that at least 1.5 million Americans have lupus. The actual number may be higher; however, there have been no large-scale studies to show the actual number of people in the U.S. living with lupus.
- It is believed that 5 million people throughout the world have a form of lupus.

## **Lupus Information Sheet (continued)**

- Lupus strikes mostly women of childbearing age (15-44). However, men, children, and teenagers develop lupus, too.
- Women of color are 2-3 times more likely to develop lupus.
- People of all races and ethnic groups can develop lupus.
- More than 16,000 new cases of lupus are reported annually across the country.

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### **What causes Lupus?**

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#### **Genes**

No gene or group of genes has been proven to cause lupus. Lupus does, however, appear in certain families, and when one of two identical twins has lupus, there is an increased chance that the other twin will also develop the disease. These findings, as well as others, strongly suggest that genes are involved in the development of lupus. Although lupus can develop in people with no family history of lupus, there are likely to be other autoimmune diseases in some family members. Certain ethnic groups (people of African, Asian, Hispanic/Latino, Native American, Native Hawaiian, or Pacific Island descent) have a greater risk of developing lupus, which may be related to genes they have in common.

#### **Environment**

While a person's genes may increase the chance that he or she will develop lupus, it takes some kind of environmental trigger to set off the illness or to bring on a flare. Examples include:

- ultraviolet rays from the sun
- ultraviolet rays from fluorescent light bulbs
- sulfa drugs, which make a person more sensitive to the sun, such as: Bactrim® and Septra® (trimethoprim-sulfamethoxazole); sulfisoxazole (Gantrisin®); tolbutamide (Orinase®); sulfasalazine (Azulfidine®); diuretics
- sun-sensitizing tetracycline drugs such as minocycline (Minocin®)
- penicillin or other antibiotic drugs such as: amoxicillin (Amoxil®); ampicillin (Ampicillin Sodium ADD-Vantage®); cloxacillin (Cloxapen®)
- an infection
- a cold or a viral illness
- exhaustion
- an injury

## **Lupus Information Sheet (continued)**

- emotional stress, such as a divorce, illness, death in the family, or other life complications
- anything that causes stress to the body, such as surgery, physical harm, pregnancy, or giving birth

Although many seemingly unrelated factors can trigger the onset of lupus in a susceptible person, scientists have noted some common features among many people who have lupus, including:

- exposure to the sun
- an infection
- being pregnant
- giving birth
- a drug taken to treat an illness

However, many people cannot remember or identify any specific factor that occurred before they were diagnosed with lupus.

### **Hormones**

Hormones are the body's messengers and they regulate many of the body's functions. In particular, the sex hormone estrogen plays a role in lupus. Men and women both produce estrogen, but estrogen production is much greater in females. Many women have more lupus symptoms before menstrual periods and/or during pregnancy, when estrogen production is high. This may indicate that estrogen somehow regulates the severity of lupus. However, it does not mean that estrogen, or any other hormone for that matter, causes lupus.

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## **Types of Lupus?**

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**Systemic Lupus Erythematosus.** Systemic lupus is the most common form of lupus, and is what most people mean when they refer to "lupus." Systemic lupus can be mild or severe. Some of the more serious complications involving major organ systems are:

- inflammation of the kidneys (lupus nephritis), which can affect the body's ability to filter waste from the blood and can be so damaging that dialysis or kidney transplant may be needed
- an increase in blood pressure in the lungs (pulmonary hypertension)

## **Lupus Information Sheet (continued)**

- inflammation of the nervous system and brain, which can cause memory problems, confusion, headaches, and strokes
- inflammation in the brain's blood vessels, which can cause high fevers, seizures, behavioral changes,
- hardening of the arteries (coronary artery disease), which is a buildup of deposits on coronary artery walls that can lead to a heart attack

**Cutaneous Lupus Erythematosus.** Cutaneous refers to the skin, and this form of lupus is limited to the skin. Although there are many types of rashes and lesions (sores) caused by cutaneous lupus, the most common rash is raised, scaly and red, but not itchy. It is commonly known as a discoid rash, because the areas of rash are shaped like disks, or circles. Another common example of cutaneous lupus is a rash over the cheeks and across the bridge of the nose, known as the butterfly rash. Other rashes or sores may appear on the face, neck, or scalp (areas of the skin that are exposed to sunlight or fluorescent light), or in the mouth, nose, or vagina. Hair loss and changes in the pigment, or color, of the skin are also symptoms of cutaneous lupus.

Approximately 10 percent of people who have cutaneous lupus will develop systemic lupus. However, it is likely that these people already had systemic lupus, with the skin rash as their main symptom.

**Drug-induced Lupus Erythematosus.** Drug-induced lupus is a lupus-like disease caused by certain prescription drugs. The symptoms of drug-induced lupus are similar to those of systemic lupus, but only rarely will any major organs be affected.

The drugs most commonly connected with drug-induced lupus are hydralazine (used to treat high blood pressure or hypertension), procainamide (used to treat irregular heart rhythms), and isoniazid (used to treat tuberculosis). Drug-induced lupus is more common in men because they are given these drugs more often; however, not everyone who takes these drugs will develop drug-induced lupus. The lupus-like symptoms usually disappear within six months after these medications are stopped.

**Neonatal Lupus.** Neonatal lupus is a rare condition that affects infants of women who have lupus and is caused by antibodies from the mother acting upon the infant in the womb. At birth, the infant may have a skin rash, liver problems, or low blood cell counts, but these symptoms disappear completely after several months with no lasting effects. Some infants with neonatal lupus can also have a serious heart defect. With proper testing, physicians can now identify most at-risk mothers, and the infant can be treated at or before birth. Most infants of mothers with lupus are entirely healthy.

### What are the Symptoms of Lupus?

Because lupus can affect so many different organs, a wide range of symptoms can occur. These symptoms may come and go, and different symptoms may appear at different times during the course of the disease. The most common symptoms of lupus, which are the same for females and males, are:

- extreme fatigue (tiredness)
- headaches
- painful or swollen joints
- fever
- anemia (low numbers of red blood cells or hemoglobin, or low total blood volume)
- swelling (edema) in feet, legs, hands, and/or around eyes
- pain in chest on deep breathing (pleurisy)
- butterfly-shaped rash across cheeks and nose
- sun- or light-sensitivity (photosensitivity)
- hair loss
- abnormal blood clotting
- fingers turning white and/or blue when cold (Raynaud's phenomenon)
- mouth or nose ulcers

Many of these symptoms occur in other illnesses besides lupus. In fact, lupus is sometimes called "the great imitator" because its symptoms are often like the symptoms of rheumatoid arthritis, blood disorders, fibromyalgia, diabetes, thyroid problems, Lyme disease, and a number of heart, lung, muscle, and bone diseases.

### Diagnosing Lupus

Unlike other chronic illnesses, trying to reach a diagnosis of lupus isn't always easy. However, today's physicians have more precise techniques and tests to detect signs of disease.

**How Is Lupus Diagnosed?** Because many symptoms of systemic lupus erythematosus (SLE) mimic those of other illnesses, lupus can be a difficult disease to diagnose. The diagnosis of lupus is based off of a combination of physical symptoms and laboratory results and for most people is not a onetime diagnosis. More often than not it is a diagnosis that evolves over time either towards more certainty that a person does or does not meet the criteria for a diagnosis of lupus.

## Lupus Information Sheet (continued)

So what is the physician looking for to help determine if the patient may have lupus?

**Common Symptoms of Lupus.** The symptoms of lupus have been described above.

**Laboratory Tests for Lupus.** Lupus is characterized by abnormalities in many laboratory test results. These abnormalities are different for every patient and they vary significantly during the course of a patient's disease. The serial evaluation of an individual's tests along with the physician's observations and the patient's history determine the diagnosis of systemic lupus erythematosus (SLE), its course, and the treatment regimen. All laboratory values must be interpreted in light of the patient's present status, other correlating laboratory test results, and coexisting illnesses. This chapter briefly describes the major tests used to diagnose and evaluate SLE and provides information on their rationale and clinical usefulness.

**What Do These Test Results Mean?** Understanding these tests and what the test results mean can be difficult. In many cases, it can take months or even years for doctors to put together all of the information that is required to make a firm diagnosis of lupus. It is important to have thorough and ongoing communication with a physician so that the proper diagnosis, whether of lupus or some other condition, can be made as early and accurately as possible.

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## Treating Lupus

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For most people with lupus, proper treatment can minimize symptoms, reduce inflammation and pain, and stop the development of serious organ damage. The information found here will help you understand the most commonly prescribed medicines today, and other drugs under investigation for treating lupus.

**Treatments for Lupus.** Health professionals continue to search for better ways to care for and treat people with lupus. Understanding what causes the disease and why certain people are more likely to develop it may one day lead to promising new treatments for, or even prevention of, lupus. In the meantime, researchers continue to look for new treatments and ways to modify existing ones so they can diminish or eliminate side effects and improve the quality of life for people who have lupus.

**Medications to Treat Lupus Symptoms.** Medications are important for managing many systemic lupus erythematosus (SLE) patients. An array of drug therapies is now available, and this has increased the potential for effective treatment and excellent patient outcomes. Anti-Inflammatories, Corticosteroids, Antimalarials,

## **Lupus Information Sheet (continued)**

Immunosuppressives medication and Anticoagulants may be used in the treatment of lupus symptoms.

**Investigational Treatments for Lupus.** People with serious illnesses who are not responding to already available treatments sometimes enroll in clinical trials to gain access to medical treatments that could be helpful. Here you will find information on Biologics, Hormones, Immunosuppressives (Immune Modulators), Monoclonal Antibodies, Organ Transplant Anti-Rejection Drugs, Stem Cell Transplantation and Tropical Immunomodulators (TIMs) therapies.

**The Best Approach to Taking Medications.** Knowing your medications and being careful to take them as prescribed can sometimes be a daunting task especially if the side effects seem to be worse than the lupus disease itself. This section will discuss how you and your health care team can work to develop the best treatment plan for you. Open communication and knowledge is the best approach to managing your lupus.

**Complementary and Alternative Medicines and Therapies.** This section looks at the role of complementary and alternative medications as a balanced approach to the management of lupus. Before you add herbs, dietary supplements, or vitamins to your diet, discuss this with your doctor, as these products may interact with drugs used to treat lupus. Dietary supplements should never be used to replace medicines prescribed to control lupus symptoms or medication side effects.

**Center for Clinical Trials Education (CCTE).** There has not been a drug approved specifically for the treatment of lupus in more than 40 years. There are a variety of reasons for this. Some are due to the complexities of the disease itself, as well as how clinical trials are designed and completed. This section will provide you with information on how Clinical Trials are increasing the understanding of lupus and the development of new treatments.

**LFA Approved Publications.** The Lupus Foundation of America Patient Education Committee has reviewed and approved a number of publications and other materials for use in educating individuals and families about lupus and its health effects.

**Final Notes of Caution.** All medicines must be taken exactly as prescribed! Forgetting to take the medicine, taking medicine in the wrong amounts or dosage, stopping a medicine, or adding dietary supplements without your doctor's approval will affect how well the drugs work and whether your symptoms of lupus can be brought under control.

## **Lupus Information Sheet (continued)**

Managing lupus is a team effort. And since there often will be several physicians involved in the care of a patient, good communication is necessary among members of your health care team.

Adapted from: <http://www.lupus.org/>, the website of the Lupus Foundation of American

These Information Sheets are designed to provide a brief overview of various medical conditions. Referring to the Information Sheets may help you communicate more effectively with other members of the Primary Care Team. The Information Sheets are by no means an exhaustive description of the disorders. If you need additional information, please engage in a more detailed search. Don't forget to consult with other members of the Primary Care Team. They are an invaluable source of information!